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Baldew, I.M.; Aldenkamp, A.P.; Suurmeijer, Th.P.B.M.; Kalsbeek, E.; Derks, H; Boer, H. de

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EFFECTS OF CHRONIC CONDITIONS ON DAILY LIFE FUNCTION OF CHILDREN AND ADOLESCENTS (ECCOCA PROGRAMME)

Imro M. Baldew¹, A.P. Aldenkamp², Th.P.B.M. Suurmeijer³, H.M. de Boer², E.M. Kalsbeek⁴, H. Koopman⁵ & Henk Derks⁴

- 1 Department of Pediatrics University Hospital, Groningen
- 2 Meer & Bosch Epilepsy Centre, Heemstede, The Netherlands
- 3 Department of Medical Sociology, University of Groningen, The Netherlands
- 4 Dutch Foundation for Chronic Diseases in Children and Adolescents, Zwolle, The Netherlands
- 5 Unit for Chronic Diseases, University Hospital, Leiden, The Netherlands

Address:

E.M. Kalsbeek,
Dutch Foundation for Chronic Diseases in Children and Adolescents
C.Z.K.
31a Sassenstraat,
8011 PA Zwolle,
The Netherlands.

INTRODUCTION

Chronic diseases are long lasting, often irreversible conditions resulting in changes in the individual and the families involved and in the quality of their interactions.

The ECCOCA programme is a joint effort in The Netherlands to study the effects of chronic conditions on daily life function of children and adolescents. Several institutions and university departments are participating. Reliable scientific research is only possible if there is no confusion about definition and diagnosis. For this reason the programme focusses on four chronic diseases: Epilepsy, diabetes, juvenile arthritis and asthma. The subsequent secondary psychosocial symptoms are significant and the burden is considerable.

In the programme eight factors are recognized associated with social, psychological and emotional development:

- the degree of dynamic shifting of paroxysmal, cyclic 'attacks' of symptomatology;
- the unpredictability of these attacks;
- the severity of the disease;
- the unpredictability of symptoms;
- the visibility of symptoms in social activity;
- the reliability of the prognosis;
- the nature of the prognosis, duration of the process;
- characteristics of the diagnostic and therapeutic regime.

In the ECCOCA programme, associated factors are seen on five levels.

I. Premorbid, existing previously.

The pre-existing factors influence adaptation and coping. There are intrinsic attributes, family factors and environmental factors.

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II. Impact of chronic disease as a life event and as a changing factor on the quality of life.

III. Specific disease symptoms and common effects.

IV. Secondary problems.

V. Interventions.

Three topics are studied at different levels.

A. The epidemiology of secondary social and psychological problems. Which children are at risk, what kind of associated characteristics can be identified? How can these children be assessed?

B. What kind of relations can be assessed between family characteristics, child-rearing practice, environmental factors and the outcome in social maturation and psychological development? How is the transition to school, adulthood, vocational training, career counselling and the labour market?

C. The development of instruments and programmes for intervention and treatment.

A selection of the results of the programme is presented in this issue by Aldenkamp, Suurmeijer, De Boer, Koopman and Derks.

